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CHAPTER 8

General discussion



Spontaneously published breast cancer stories on the Internet are a unique source of support and information for other breast cancer patients for three reasons: 1) these stories are usually complete stories; 2) the writers are not selected and their stories are not edited; and 3) the number of these stories is large and continuously increasing. According to the narrative approach [1], social comparison theory [2], and social cognitive theory [3], reading stories written by others in a similar situation may have the most positive impact on how the reader copes with her own situation. However, such stories can be difficult to find. Therefore, the primary aim of this thesis was to gain insight into which search facilities help breast cancer patients find spontaneously published stories written by other patients in a similar situation to themselves.

This was examined following a user-centred design: users of search facilities (i.e., the patients) were involved in each phase of the research. This ensured that the search facilities were tailored to the users' needs and preferences, rather than forcing users to adapt their search behaviour to search facilities developed without their involvement. Concretely, we examined which breast cancer patients spontaneously publish their story online and which themes they write about in their stories (*Chapter 3*), and how these stories are presented and disclosed on websites (*Chapter 2*). We then examined which topics and writer characteristics patients prefer to search for (*Chapter 4*) and translated these preferences into search facilities. Finally, we examined which search facilities had the most positive effects on patient satisfaction and search success, and how patients actually searched for stories written by others (*Chapters 5-7*).

In this chapter, we will reflect on certain aspects of spontaneously published stories on the Internet, using the findings from *Chapters 2 and 3*. Secondly, on the basis of the results presented in *Chapters 4-7*, we will discuss aspects of search facilities for patient stories. Subsequently, we will describe methodological issues and limitations and practical implications. Finally, we will conclude the chapter with an overall conclusion and reflection.

Spontaneously published breast cancer stories

In this thesis, spontaneously published breast cancer stories are defined as first-person texts written by breast cancer patients in which the patients describe their experiences with the illness trajectory, their feelings about having breast cancer, and how they cope with the disease, and which they published at a given moment on the Internet as a 'completed' story (i.e., without later additions and not as part of an interactive forum). The stories can be published and read anonymously.

Stories play an important role in how people learn about the world, and we are used to telling and hearing them from childhood onward (e.g. [4]). More specifically, patient stories contain valuable patient expertise on strategies for coping with day-to-day personal health issues gained through trial and error of the lived experience [5]. The Internet allows all breast cancer patients who want to share their stories with others to do so by publishing their story on websites that offer this option. Other patients can read these spontaneously published stories for information and support. The studies in *Chapters 2 and 3* highlight a number of important aspects of spontaneously published

stories. Here we discuss the aspects ‘representativeness’, ‘authenticity’ and ‘reliability’. In this context, we also discuss the role of physicians and new developments on the Internet.

Representativeness

To gain an idea of the writers and their stories, we conducted a content analysis of all 167 breast cancer stories available on the Dutch-language website “De Amazones” [6] at the time of our study (*Chapter 3*). We found that women were more likely to be a writer if they had been diagnosed at a younger age, had undergone a mastectomy, or were in the first treatment period. The analysis of the themes in the stories showed that some themes were addressed less often than would be expected based on their prevalence in quantitative studies. For example, the theme ‘body image and sexuality’ was discussed in 20-25% of the stories, while prevalence studies showed that approximately half the patients experience problems regarding this theme.

Our findings point to a spontaneous selection of both the patients who publish their story on the Internet and the themes they write about. One explanation for the finding that writers were relatively often in the first treatment period might be that patients find themselves in the middle of the coping process during this period and therefore feel a strong need to write [7-12]. Regarding the topics, patients mainly write about topics relating to their demographic and disease characteristics, topics that are hard to handle, or topics with which they still have to cope (see also *Chapter 4*). Furthermore, for some patients the Internet may provide the privacy and anonymity to write about more personal topics than they would do in other settings (e.g. [13]).

In conclusion, our content analysis of the stories on the website of De Amazones (*Chapter 3*) indicates that spontaneous selection occurs with regard to both the patients who publish their story and the topics about which they write. The question arises whether this spontaneous selection poses a problem for readers who want to use the stories for support and information. With regard to patient decision aids that include patient stories there is a clear consensus among an international team of patients, practitioners, policy makers, and researchers that a range of patient perspectives and experiences should be included [14]. This principle has been applied on the website Healthtalkonline (formerly DIPEX) [15], where the developers have used maximum variation sampling when interviewing patients for their website to ensure that a wide range of patient perspectives and experiences are represented [16]. They thus offer a set of stories that is qualitatively representative: for each topic that appears to be of interest in coping with the disease, an approximately equal number of positive and negative perspectives/experiences is presented [16]. However, even such a ‘balanced’ presentation of views can potentially give false impressions [17]: the number of positive and negative experiences related to each topic seems to be equally balanced, while in reality perhaps 90% of patients had negative experiences regarding a particular topic. Therefore, it might be argued that readers are best served by a set of stories that meets quantitative representativeness. Thus, if, for example, a quarter of patients are struggling with topic x, this topic should be covered in about a quarter of the stories. Nonetheless, even if a set of stories meets criteria for qualitative or quantitative representativeness, it remains unclear whether this representativeness will reach the reader since they may

select only certain stories to read and thus may not read the whole set of stories. This is illustrated by our interviews (*Chapter 4*) in which patients mentioned that they did not read stories about patients with metastatic cancer to avoid being confronted with this subject. Moreover, a reader can select stories from other sources of information besides a single website with a representative set of stories and, consequently, the representativeness of the original stories may be affected by reading further stories on other websites. On the other hand, an advantage of websites with a set of stories that does meet qualitative or quantitative representativeness is that it enables the reader to interpret the representativeness of the set of stories.

For a set of spontaneously published stories, representativeness will always remain an issue due to the above-mentioned self-selection of writers and topics and due to the dynamic nature of such a story set where stories are constantly being added and removed. For example, the 2013 addendum to *Chapter 2* shows that, of the 12 sites described in 2006, three no longer exist and four no longer contain patient stories. Thus, five of the twelve sites still contain breast cancer stories. On one of these sites, the number of stories increased from 49 to 790 [6]. In addition, in 2013 twelve new websites with patient stories were found. In conclusion, the addendum illustrates the dynamic nature of patient stories online.

Authenticity

In our study on how Dutch-language breast cancer stories are disclosed on websites (*Chapter 2*), we defined authentic stories as those written or told by real patients. The addendum to the study, written in 2013, revealed that the stories on three of the sixteen websites examined could definitely be ascribed to real patients since these patients had been filmed during hospital visits (*Chapter 2*). However, the literature shows that there are different opinions about authenticity. Some feel that even the authenticity of stories written by real patients can be questioned since, in their stories, patients may tend: a) to apply a little self-deception in order to feel better about their situation; b) to portray themselves more favourably than they really are; and/or c) to comply with the dominant narrative conventions of their culture and society, such as the restitution narrative (patient gets sick, patient receives medical intervention, patient recovers and returns to pre-illness life) or the quest narrative (disease is required for a positive change) [12;18;19]. On the other hand, others feel that regardless of what drives the story, it remains the story the patient wanted to tell and, as such, it is authentic [18]. Moreover, stories that are not written by real patients might also offer support. Research on social comparison shows that people are able to compare themselves with non-existent persons because they are able to cognitively construct others [2]. The aspects discussed above raise the question as to which criteria make a story authentic and how important this authenticity is for the readers.

Reliability

Our study of sixteen websites with Dutch-language breast cancer stories (*addendum to Chapter 2*) revealed that the stories on six websites had been reviewed by an editor prior to publication. The question is whether review by an editor results in reliable stories. As discussed above, one view is that stories written by patients are always 'true', because

stories describe the patients' experiences [18;19]. However, besides patient experiences, stories also contain medical information. The medical information described by patients in their stories may differ from the conventional medical standards. To prevent the stories containing unconventional medical information, an editor/health care professional may review the stories prior to publication to ensure that the medical information is reliable. However, in practice this might be difficult for stories that are published spontaneously, because it is not known when new stories will be added. Moreover, those who publish their own story online may feel hurt if their story is criticized or simply corrected for facts [4], since a story is a very personal form of expression.

It is not known how many spontaneously published stories contain medically incorrect information. Studies on the accuracy of medical information in online support groups have shown that only few postings are false or misleading [20;21] and that most false or misleading statements are rapidly corrected by participants in subsequent postings [20]. However, for spontaneously published stories, correction by others is not possible due to the absence of an interactive component. Another type of medical information covered by stories, and possibly of more concern than medical inaccuracies, is the writer's treatment plan. A reader can mistakenly think that she needs the same treatments as the writer, because the writer's situation seems very similar to that of the reader. However, the writer may have omitted to report important background information that was decisive in determining her treatment plan. This issue will not be remedied by editing a story, because the bottleneck lies in the interpretation by the reader.

Role of health care professionals

We saw that readers of spontaneously published stories on the Internet may be affected by the stories' representativeness, authenticity and reliability. It is important to discuss the role of health care professionals in how these stories are interpreted by patients. Studies show that many cancer patients discuss information that they find on the Internet with their health care professionals [22-24]. Some physicians react positively: patients are better informed about their disease and treatment options and it strengthens the doctor-patient relationship because it becomes a partnership rather than a process of one-way information provision. Other physicians feel threatened in their expertise, have difficulty discussing the information, and think that it makes patients anxious and confused [22-24]. Therefore, it is important for physicians to reflect on how to deal with patients who have read other patients' stories on the Internet and who have questions about these stories or who believe they should receive the same treatments as the writer.

Another issue is the role of physicians in referring to health-related websites, such as websites with patient stories. Research [22] shows that physicians do not refer to health-related websites often and that they seldom or never refer to online support groups. One reason for this is that many physicians find it difficult to stay up to date with reliable Internet sites for patients [22]. Given the above-mentioned aspects of spontaneously published stories, it can indeed be difficult for physicians to determine which websites with patient stories they can 'safely' refer their patients to. One solution may be to develop a quality label for websites with patient stories, providing readers with information about the representativeness, authenticity and reliability of the set of stories. Such quality

labels already exist for websites with medical information, for example the HONcode developed by the Health On the Net Foundation [25] and 'ZegelGezond' developed by a Dutch organization [26]. However, for a site with spontaneously published patient stories it may be difficult to keep a quality label up to date, since the compilation of the set of stories changes constantly. Therefore, another solution may be to develop a checklist with a set of criteria that enables readers to focus on those aspects that are important for a set of patient stories. For example, readers should check whether the stories contain both positive and negative experiences and whether information is provided about why patients decided to share their story. Such checklists have already been successfully developed for patient decision aids. For example, the International Patient Decision Aid Standards (IPDAS) Collaboration has developed a checklist with a set of criteria that enables users of a decision aid to assess its quality [14]. The outcome of this research on patient decision aids may also be helpful in the development of checklists for spontaneously-published patient story sets.

New developments in accessing patient experiences on the Internet

In this thesis, we focused on websites with 'completed' spontaneously published breast cancer stories. However, there are various other forms in which patients can read experiences on the Internet.

The Internet provides patients with a broad range of online support groups, which have been widely investigated (e.g. [27-30]). The experiences published in such online support groups differ from the stories focused on in our research since online support groups allow patients to pose questions and/or reply to each other. Also, the excerpts in online support groups are usually shorter than complete stories.

In the last few years, there have been several new developments regarding patient experiences on the Internet. One example is the website PatientsLikeMe [31], which is an online community built to support information exchange between patients. The site provides customized disease-specific outcome and visualization tools to help patients understand and share information about their condition [31]. Another development is the opportunity for patients to publish their personal story on the Internet through videos on YouTube [32].

More recent developments are social media, such as Twitter and Facebook, which serve many functions including health-related purposes, such as sharing illness experiences [33-37]. Social media enable users to post messages for everyone to read (public) or only for certain friends or followers (customized) and allow users to follow individuals and organizations in order to receive new posts from these people or groups. In addition, users can forward possibly relevant posts to friends or followers. The use of social media for sharing illness experiences raises new questions: for example, how can patients find each other, how can they retrieve relevant experiences posted by others, and how should they deal with privacy issues when using real name accounts.

Moreover, the Internet is no longer a medium that can only be accessed from behind a computer screen. With the introduction of the Internet on smartphones, everyone has the Internet at their fingertips, wherever they are and whatever they are doing. Smartphones also offer the ability to support patients through apps. For example, the

Trimbos Institute is developing an app for women newly diagnosed with breast cancer that provides mental support during diagnosis and treatment [38].

The forms described above are characterized by consisting of (relatively) short fragments, having interactive components, being moderated, and having a continuous flow of communication (threads). The ‘completed’ stories, focused on in this thesis, are characterized by the absence of an interactive component and by being non-moderated. In terms of these ‘completed’ stories, we found that if these stories were disclosed using a ‘story topic’ search facility, the stories retrieved had a positive effect on patients’ self-reported coping with cancer (*Chapter 5*). Future research could investigate whether this finding can be extrapolated to the various other forms of online patient experience-sharing. Moreover, it could be investigated which particular features of these other forms of online patient experience-sharing have positive effects on writers and readers and, more specifically, how they impact a reader’s coping with cancer.

Search facilities

Our study from 2013 on how stories are presented on websites (*addendum to Chapter 2*) revealed that two of the sixteen websites offer a search facility for writer characteristics [6;39], while none offer a search facility using content keywords. Nine websites offer a full-text search facility (e.g. [40]). Full-text search engines only retrieve documents in which the word that is searched for occurs literally (for example, a search for ‘bestraling’ [*radiation*] will retrieve no stories in which this is called ‘radiotherapie’ [*radiotherapy*]).

The question is how a lack of search facilities affects the reader. Our interviews (*Chapter 4*) showed that breast cancer patients prefer story fragments about specific topics from patients with particular personal and/or disease characteristics. Without search facilities, such stories might be difficult to retrieve. Moreover, our online randomized controlled experiment (*Chapter 5*) showed that search facilities for story topics (based on manual indexing) and writer characteristics contributed positively to readers’ satisfaction with the search process (outcome measure 1) and the stories retrieved (outcome measure 2). The ‘story topics’ search facility also contributed positively to patients’ self-reported coping with breast cancer (outcome measure 3). However, this positive effect was not found for the ‘writer characteristics’ search facility. Overall, the ‘story topics’ search facility had markedly more positive effects per outcome measure than the ‘writer characteristics’ search facility, and combining the two search facilities barely increased the positive effect. It might therefore be concluded that, for stories to provide readers with support and information, they should, as a minimum, be disclosed according to story-specific topics.

On the other hand, it is striking to note that analysis of the log data from the online experiment revealed that, per search, patients were more likely to search for writer characteristics than for topics (*Chapter 6*), even though the online experiment had shown that searching for topics had far more positive effects on satisfaction and search success than searching for writer characteristics (*Chapter 5*). So, given these positive effects, why do patients not search for more topics per search? In the interviews (*Chapter 4*), one patient explained that she wanted to be able to search for writer characteristics

(treatment undergone) to gain information about a topic (decision-making about treatment). Thus, one explanation might be that writer characteristics and story topics cannot be clearly distinguished from one another when searching for stories. Another explanation might be that the nature of a topic is more important than the number of topics, while for writer characteristics the number might be more important than the nature. In other words, the higher the number of writer characteristics searched for per search, the more specific the search results will be in terms of writer characteristics. This is important in social comparison, since social comparison theory suggests that comparison with a writer on a specific dimension (regardless of the direction of the comparison) will have the most impact when other dimensions of the writer, such as their personal situation or characteristics, are similar to those of the reader [2;41;42]. To ensure cost-effective implementation of search facilities, it is important to examine which writer characteristics and which topics should, as a minimum, be included in search facilities to maintain the positive effects on satisfaction and search success.

Furthermore, the *addendum to Chapter 2* showed that there is an increase in the number of patient videos in which patients tell their story. The question arises how these patient videos could be made accessible to other patients.

Selection of writer search characteristics

The analysis of the log data (*Chapter 6*) showed that patients predominantly search for stories by writers with similar demographic and disease characteristics to their own. This might enable patients to identify with these writers, whose stories they may therefore find most informative and supportive. The question arises whether there are other story characteristics that may be relevant for a reader to identify with the writer, such as the writer's writing style, personality and/or coping style. Based on social comparison theory [2] and social cognitive learning/modelling [3], which suggest that people can learn from observing the behaviour of others (vicarious learning), stories will be more appealing to the reader if the reader observes similarities between him/herself and the writer. An interesting theme for future research would therefore be whether search facilities that include aspects such as writing style, personality and/ or coping style increase the usefulness and impact of stories retrieved. Such research would face the challenging task of clearly defining these aspects and tagging stories according to these definitions.

Feasibility and responsibility

Two challenges in implementing search facilities for spontaneously published stories are feasibility and responsibility. Regarding feasibility, it is important to assess the most cost-effective balance between, on the one hand, the number and type of search facilities (topics, writer characteristics and/or other characteristics) and, on the other hand, the potential positive impact that stories retrieved by these search facilities may have on readers. Another cost-effectiveness issue is tagging stories efficiently to build the search facilities (tagging by human reading and/or semi-automatic tagging).

Regarding responsibility, the question arises as to who will implement the search facilities and who will keep them up to date, as this costs both time and money. Two cost-effective solutions for building search facilities seem to be available. Firstly, writers may tag their own stories, for example by using the coding scheme that was developed

for our content analysis (*Chapter 3*). Nowadays, content tagging by users is common on the Internet; the distinction between website builders and website users is less clear. On Twitter and Facebook, for example, users can tag their own posts and those of others. There are also social bookmarking websites that collect information about the content tags assigned to websites by users and which may serve as an alternative to search engines [43]. Another solution might be a technique like Latent Semantic Indexing (LSI). This mathematical technique places stories and search queries in a multidimensional space: distances between them provide information about similarity in content. No human reading is necessary to tag and categorize stories and searching involves typing natural language queries. Our exploratory study showed that patients used the features of the LSI search facility and that they were quite satisfied with the search process (*Chapter 7*). However, the LSI was also associated with some difficulties. For example, fine-tuning the multidimensional space was time-consuming and one participant indicated that she saw no relationship between her search query and the stories retrieved by LSI. Thus, more research is needed before LSI can be used as a search facility to find relevant stories.

Methodological issues and limitations

The research described in this thesis is a combination of qualitative and quantitative studies. Following a user-centred design, we involved the user in the process of developing the search facilities from the outset. The results of one study served as input for the design of the next study: the results of the qualitative interviews with breast cancer patients (*Chapter 4*) served as input for the design of the online randomized controlled experiment (*Chapter 5*), and the results of the online randomized controlled experiment triggered the idea for exploring the use of Latent Semantic Indexing as a search facility (*Chapter 7*). We consider this combination of qualitative and quantitative studies and the user-centred design to be strong methodological features of our research.

However, we wish to critically address two methodological issues. The first issue relates to researching the Internet. Firstly, it is impossible to examine the entire Internet: to keep the research manageable, one needs to focus on a defined part of the Internet. We focused on several Dutch websites with breast cancer stories. Secondly, websites are constantly changing, while researching a website is conducted at a particular moment in time. The set of stories on the De Amazones website, for example, consisted of 49 stories in 2005 (*Chapter 2*) and grew to 167 stories by 2007 (*Chapter 3*) and 790 stories in 2013 (*addendum Chapter 2*). Besides the number of stories, the way in which stories are presented and disclosed might also change. The *addendum to Chapter 2* shows that, in 2013, two websites offered a search facility for writer characteristics, while in 2006 none of them offered such a search facility. However, as in 2006, in 2013 no websites offer a search facility for story topics (based on content keywords). Finally, it is important to realize that our online experiment (*Chapter 5*), although coming close to searching a real website, remains an experimental setting that could have affected the participants' behaviour and opinions.

A second methodological issue is that the qualitative study and the exploratory study involved relatively small numbers of participants. We interviewed 26 breast

cancer patients about their preferences for topics and writer characteristics (*Chapter 4*). However, it is important to mention that the results of the interviews are not isolated, but were included in the online experiment and resulted in positive effects on search satisfaction and search success (*Chapter 5*). In the LSI study, 23 breast cancer patients participated (*Chapter 7*). This study was exploratory in nature and more research is required before LSI can be used as a search facility for stories.

Practical implications

The research in this thesis has led to three practical implications:

- If health care professionals decide to refer their patients to websites with spontaneously published breast cancer stories, it is important that they discuss these websites' opportunities and risks with their patients. As mentioned earlier, opportunities and risks lie in the representativeness, authenticity, and reliability of stories and in the availability of search facilities.
- Organizations and individuals who offer spontaneously published breast cancer stories on their websites are advised to provide search facilities to enhance the accessibility of the stories for readers. Since, in patient decision aids, patient stories are being used increasingly frequently [44;45], developers of these aids may also consider including search facilities for stories. Appropriate search facilities increase the likelihood that a reader will find relevant stories that provide support. Currently, the most practical and cost-effective way to implement search facilities might be to ask the patients themselves (writers and readers) to tag the stories according to, for example, writer characteristics and/or topics.
- This thesis examined online breast cancer stories, but it can be assumed that the two above-mentioned practical implications can also be applied to online stories written by patients with other diseases. Stories on the Internet might be especially helpful in rare diseases or for men with breast cancer [46], where the probability of meeting a fellow patient in real life is small [47].

Overall conclusion and reflection

The Internet has a role in exchanging 'complete' illness stories. There are patients who spontaneously publish their story on the Internet and there are other patients who read these stories. Although the writers and the readers may have different intentions, this does not present a problem as both writing and reading serve certain functions. In my opinion, it is important that patients make their own decision about whether they want to publish their story on the Internet or whether they want to read stories written by other patients. Important others, such as health care professionals and family members, may recommend patients to write and read stories, but patients should not feel 'pressured' to do this.

Spontaneously published stories on the Internet provide both opportunities and risks. Opportunities lie in the possibility that stories may serve a functional purpose,

for both writers and readers, such as offering emotional support or providing models by which to solve problems. Therefore, patients who feel the need to publish their own story or to read stories of others should continue to do so, and publishing and reading stories should not be regulated (an impossible task in itself). The research in this thesis has shown that the opportunities provided by online stories can be increased by implementing relevant search facilities to retrieve stories: participants indicated that stories retrieved using a 'story topics' search facility had a positive impact on coping with the disease. In view of this finding, I believe that there should be greater focus on developing search facilities for stories, since there is a very large number of freely-available online patient stories that may offer support and information to other patients. Not making use of these stories is a missed opportunity. Professionals should therefore facilitate patients in finding relevant stories written by others by implementing search facilities that fulfil patient preferences (user-centred design). Stories that are not adequately disclosed, for example due to a lack of search facilities, will have no impact on a reader.

Possible risks regarding spontaneously published stories on the Internet relate to the representativeness, authenticity and reliability of stories. There are two approaches to limit these risks. The first approach is to regulate which patients publish their stories online. However, this is neither desirable nor possible and therefore there will always be patients who publish 'deviant' and 'unconventional' stories. The second approach is to empower the readers. Since Internet use is part of our everyday life and since we are used to hear stories from childhood onwards, my expectation is that readers already have quite some skills to assess online stories and that there is common sense that not all stories reflect reality. Nonetheless, to further enhance readers' skills in assessing patient stories, quality labels might be assigned to websites with patient stories or a checklist with criteria to assess websites with patient stories could be developed. Since quality labels may be difficult to keep up to date because stories are spontaneously published at unknown time points, a checklist may be preferable.

We have observed many new developments on the Internet through which patients can share their illness experiences. However, my expectation is that spontaneously published 'completed' stories will continue to coexist alongside these new developments, since there will always be patients who want to publish their whole story at once, without interacting with others and without their story being moderated. Future research could focus on the effects that the features of these different forms of online patient experience-sharing (i.e., completed story vs. short fragment, interactive vs. non-interactive, moderated vs. non-moderated, etc.) have on their writers and readers.

As mentioned above, it is neither desirable nor possible to regulate spontaneously published stories on the Internet. However, I do believe that it is important to maintain an open discussion about the opportunities and the risks presented by spontaneously published illness stories on the Internet. All four parties involved should participate in this discussion: patients (both writers and readers), patients' family and friends, organizations and individuals who offer stories on their websites, and health care professionals. In addition, new developments in sharing illness experiences, such as Twitter and Facebook, should also be discussed. I think it is particularly important to discuss each group's role and responsibilities in the context of patient experiences on

the Internet. Such discussions may start spontaneously, as illustrated by the case of a family member who raised the ethical issue of posts about an ill relative on a real name account on Facebook [48]. Moreover, patient organizations may also play an important role in initiating discussions about this theme. A powerful discussion may help to increase the opportunities and reduce the risks presented by online patient experiences. In this discussion, the question of how stories can be made accessible to patients so that patients can quickly and easily find stories written by similar others should play a central role.

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